

# Terms of Reference

## VicHip Consumer Advisory Group

The [Victorian hip dysplasia registry](#) (VicHip) Consumer Advisory Group (CAG) is a team of passionate members from the hip dysplasia community. They work together with a shared goal to improve the lives of individuals with hip dysplasia and enhance the quality of hip care and services in Victoria.

Many of the group's members are volunteers who generously donate their time and input. We are immensely grateful for your contributions.

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These are the Terms of Reference (TOR) for our group. It outlines our objectives, activities and collaborative approach to ensure our group's efforts are effective and meaningful.

### Purpose and function

The CAG plays a vital role in connecting VicHip with its consumers. By maintaining a consumer-focused approach, the CAG helps VicHip make informed decisions and enhances its ability to meet its consumers' needs and interests. The following functions ensure that VicHip delivers the best possible registry and research outcomes relevant to its consumers and positively impacts the hip dysplasia community.

The CAG

1. Empowers VicHip consumers to actively participate in the development and ongoing improvement of the registry, its research and initiatives.
2. Help strengthen VicHip's operations, recruitment and engagement strategies, research methodologies and overall experience in VicHip.
3. Provides valuable insights, feedback and perspectives based on the personal experiences of VicHip consumers.
4. Reviews and advises on the acceptability of study materials, approaches, proposed changes and methods of disseminating research findings to ensure they are accessible, understandable, culturally appropriate and considerate of consumer needs.

### Term of duration and review

- This TOR is effective from 18 April 2024 and will continue until terminated.
- If VicHip decides to dissolve the CAG, all members will be notified in advance, and appropriate arrangements will be made to ensure the completion of any outstanding activities.
- These TORs may be amended or updated as necessary by mutual agreement between VicHip and the CAG, and changes will be communicated transparently.
- These TORs will be reviewed periodically to ensure the CAG's effectiveness in achieving its objectives.

## Membership

- The CAG is a group of diverse individuals representing various demographics, backgrounds and experiences to ensure comprehensive feedback.
- Membership is voluntary and open to anyone involved in VicHip, may benefit or be impacted by VicHip, has a direct interest in its process, decisions or outcomes, or can positively influence VicHip.
- We welcome anyone interested in contributing to consumer-focused research on hip dysplasia to join us. This might include the following consumers, but not limited to:
  - hip dysplasia patients and families
  - VicHip registry participants
  - community members (parents/public)
  - partner sites/hospitals
  - health professionals and services
  - research partners, collaborators and students
  - policy makers.

It is important to note that if you or your child has hip dysplasia, being a member of the CAG will not directly benefit you in terms of individual medical treatment. However, your contribution to the group can help improve the quality of care and treatment outcomes for future patients.

## Expectations of members

- Participate in discussions (eg. meetings, workshops, focus groups) and surveys to share your insights and preferences, in person or virtually.
- Provide honest feedback and recommendations in a timely manner.
- Maintain confidentiality and respect the privacy of CAG members.
- Be a champion for VicHip.
- Disclose any potential conflicts of interest.

## Decision-making and governance

- Decisions related to CAG's operations will aim to achieve consensus whenever possible while respecting differing viewpoints.
- VicHip will consider and give due weight to the recommendations provided by the CAG in its decision-making processes.
- The Senior Clinical Research Coordinator of VicHip will lead the CAG and chair meetings.
- Different designated members of the VicHip team will help facilitate communication within the CAG.
- VicHip will provide necessary resources, such as meeting facilities, technical support, and administrative assistance to facilitate the functioning of the CAG.

## Contact

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